Yellowknife Association for Community Living *Respite Service*

Report 2003-2005

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1.0 Purpose

This report is to provide the Ministers and Members of the Legislative Assembly with the outcomes of the evaluation of the Yellowknife Association of Community Living (YKACL) Respite Pilot Project while respecting the rights and confidentiality of the respite recipients and caregivers.

The purpose of the evaluation of the Pilot Respite Service (the Service) was to ensure that the Service was providing a safe, individualized, and flexible respite support to families/primary caregivers as well as offer individuals with disabilities more opportunities for inclusion activities in Yellowknife, Dettah, and N'dilo. In determining its impact, three key issues were evaluated: (1) the manageability, (2) the sustainability, and (3) the affordability of the Service. The evaluation also covered the extent to which the Service has been able to achieve its goal and stated outcome.

2.0 Context of the Respite Service

2.1 Background

Following the work of an advisory group composed of representatives from YKACL, the NWT Council of Persons with Disabilities, the Centre for Northern Families, and government; 19 families joined together for a one-day focus group in April 2003 to identify the need for a respite service in Yellowknife and provide some answers on how to address it. During this one-day focus group, the families developed a definition of respite:

> *Respite is an essential support service that provides planned relief for primary caregivers, families, and the people with disabilities that they care for. This relief is necessary to decrease burn out, stress, and crisis in care, and to allow the caregivers to be able to provide the best possible support and care to a person with a disability. This enables people with disabilities to have the best quality of life.*

A goal for a NWT Respite Service was also defined:

> *To provide safe, individualized, and flexible respite support to families/primary caregivers as well as offer individuals with disabilities more opportunities for inclusion in community activities in Yellowknife, Dettah, and N'dilo.*

The following definitions for impairment and disability as classified by the World Health Organization in 1980 formed the basis for the proposal for a respite service in Yellowknife, NT.

Impairment: any loss or abnormality of a psychological or anatomical structure or function.

Disability: any restriction or inability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being.

2.2 Eligibility

Utilizing the goal and definitions noted above, the Service is available to families who are supporting people with disabilities of all ages who reside in Yellowknife, Dettah, or N'dilo. It is an open referral process, therefore allowing a family to be referred to the Service by another disability organization, a family doctor, Stanton Regional Hospital, Yellowknife Health and Social Services Authority, a school district, or social

development program. As well, families may request respite directly from the Service.

The Respite Coordinator completes a short and family friendly intake assessment form with the family to identify the family's particular needs. Once this is completed, the process to determine the amount of respite hours is initiated and determined by the intake committee.

2.3 Description of the Respite Service

Families in Yellowknife emphasized that respite should offer those with disabilities time away from their caregivers in the same way that it offers a break for the family caregivers. As such, the service provides opportunities for those with disabilities and their families to participate in community activities.

Each worker is expected to have his or her First Aid, Cardio Pulmonary Resuscitation (CPR), and a criminal records check completed once per year. Training for each respite worker is also provided by the service and includes several modules in the following 11 areas:

1. Background on disabilities;
2. Sensitivity training;
3. Complex situations;
4. Communication;
5. Placement process;
6. Training provided by Family;
7. Review of policies and procedures;
8. Review of all forms;
9. Community Inclusion;
10. Back Care Education; and
11. FASD Training.

Each family is allocated hours based upon identified needs. There are no fees charged to the families for the services provided.

3.0 Analysis

3.1 Is the Respite Service Manageable?

Strengths

The main strength of the Service is that it meets the needs of those families who are receiving the Service. The response provided was that the Service was able to meet staff/relief/support needs while also providing recipients with inclusion opportunities.

Challenges

Due to the complexity of the first 13 months of the implementation phase of the service the ability to utilize the allocated hours was difficult.

3.2 Is the Respite Service Sustainable?

Strengths

One of the identified strengths of the Service related to sustainability in that overall the caregiver and the recipients were satisfied with the service being provided.
Other identified strengths were the level of involvement Caregivers had in the decisions regarding the respite care received and that it filled a service gap for families with children and adults with disabilities.

Challenges

The Service has faced difficulties in keeping within the original parameters of social respite. For example, some services that were provided could be interpreted as duplicating a home care service.

Other concerns were that not all of the Respite Workers providing service had valid CPR and First Aid Certificates. It was also identified that some workers were providing care for others not in the program at the same time they were providing respite services.

There were limited reports of the Service addressing its goal of providing more opportunities for inclusion in community activities (i.e. only 36% of Caregivers and 40% of Respite Workers reported that the services took place in the community). The emphasis of the Service was to provide the Caregivers with a break.

The four main themes that emerged from the analysis included:

i. Lack of core funding and/or cost of the Service – To date, the Service has been funded on a proposal basis via Contribution Agreements. There has been no commitment provided by the Department or YHSSA to fully fund the amount YKACL requested for 2005-2006 until the completion of this evaluation.

ii. Self-identifying intake procedures – The intake process has consisted of Caregivers filling out a self-identified Intake Assessment Form. The Respite Coordinator summarizes the information and makes recommendations to the Intake Assessment Committee who decides whether the family's needs are low, medium or high based on the summary with no specific criteria to follow.

iii. The Intake Assessment Committee then reviews the eligibility form to determine the amount of hours a family should be allocated. No family to date who has required respite service has been denied hours, except for the individuals on the waiting list.

iv. As of March 2005, there were 12 families identified on the waiting list. The majority of the families on the waitlist have not been through the assessment phase to determine their needs.

3.3 Is the Respite Service Affordable?

Strengths

A strength of the Service is that it is affordable and it remained within budget from August 2003 to March 2005.

Challenges

It was difficult to determine if families who had access to other programs were allocated fewer hours of respite service than those families who had no other supports.

Another challenge of the Service in being affordable is the extent to which it is utilizing its allocated hours. The cost analysis based on the utilization of hours strongly identified that the greater the utilization rate, the lower the cost of the service. The extent to which the cost of this service effectively compared to other services was not identified as part of this evaluation.

4.0 Recommendations

1. Revisit the goal of the Service to ensure that offering individuals with disabilities more opportunities for inclusion in community activities in Yellowknife, Dettah, and N'dilo is something the Service should retain within its goal.

2. Continue to build upon the Respite Worker Resource Manual and the Family Handbook to develop policies and protocols for the Service. These policies and protocols should be approved by the funding agency.

3. Ensure the necessary qualifications and skills of all the Respite Workers meet the criteria developed.

4. Evaluate the extent to which the allocation of hours is based on the actual need usage of the families and restructure accordingly.

5. Continue providing services to those that are utilizing their hours.

6. Analyze the utilization of hours on an ongoing basis to determine effective and efficient use of respite hours.

7. Implement a process to closely monitor actual revenue and expenditures of the Respite Service.

8. Develop policies and procedures in order to address potential emergency cases.

9. Develop and implement an ongoing monitoring and evaluation framework.

5.0 Conclusion

When the various Service strengths and challenges are analyzed it is apparent that it is meeting the needs of families who access the Service. In particular, the Respite Service is meeting the needs of the Caregivers to the extent that they have reported that the respite support being provided has been safe, individualized, and flexible.

What is not as apparent is the ability of the Service to provide individuals with disabilities more opportunities for inclusion in community activities. The evidence supporting this conclusion suggests a need to revisit the goal to determine if this activity is something that should be part of the Service.

Once the actual goal is well defined, it will be easier for the Service to address its inherent challenge faced in its pilot phase – the need to develop strong parameters. By building upon the Respite Worker Resource Manual and the Family Handbook to develop policies and protocols for the Respite Service, it would be better placed to ensure the validity and sustainability of the Service.

Stakeholders have begun to address the recommendations provided in this report, especially considering the need to address the respite needs of those families on the waiting list.

It is expected that once the recommendations are addressed, the Respite Service can continue to function as it was originally intended, with the advantage of being able to validate itself as a planned and structured Service.